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## REVIEW



# Achieving patient engagement in multiple sclerosis: A perspective from the multiple sclerosis in the 21st Century Steering Group

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**Abbreviations:** CIS, clinically isolated syndrome; CPS, control preference scale; DMTs, disease modifying therapies; JCV, JC virus; MRI, magnetic resonance imaging; MSDS 3D, Multiple Sclerosis Documentation System 3D; MSIF, Multiple Sclerosis International Federation; NABs, neutralizing antibodies; NEDA, no evidence of disease activity; OCD, obsessive-compulsive disorder; OCT, optical coherence tomography; PROs, patient-reported outcomes; RIS, radiologically isolated syndrome; SCHIP, State Children's Health Insurance Program; T2T, treat-to-target; WHOQoL-BREF, World Health Organization Quality of Life instrument (short form)

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**KEYWORDS**

Multiple sclerosis;  
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making;  
Care;  
Management

**Abstract**

While advances in medicine, technology and healthcare services offer promises of longevity and improved quality of life (QoL), there is also increasing reliance on a patient's skills and motivation to optimize all the benefits available. Patient engagement in their own healthcare has been described as the 'blockbuster drug of the century'. In multiple sclerosis (MS), patient engagement is vital if outcomes for the patient, society and healthcare systems are to be optimized. The MS in the 21st Century Steering Group devised a set of themes that require action with regard to patient engagement in MS, namely: 1) setting and facilitating engagement by education and confidence-building; 2) increasing the importance placed on QoL and patient concerns through patient-reported outcomes (PROs); 3) providing credible sources of accurate information; 4) encouraging treatment adherence through engagement; and 5) empowering through a sense of responsibility. Group members independently researched and contributed examples of patient engagement strategies from several countries and examined interventions that have worked well in areas of patient engagement in MS, and other chronic illnesses. The group presents their perspective on these programs, discusses the barriers to achieving patient engagement, and suggests practical strategies for overcoming these barriers. With an understanding of the issues that influence patient engagement in MS, we can start to investigate ways to enhance engagement and subsequent health outcomes. Engaging patients involves a broad, multidisciplinary approach.

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**1. Introduction**

In 2011, the multiple sclerosis in the 21st Century initiative was established; it is led by a Steering Group of international experts in MS treatment and management, and by patient group representatives. The initiative seeks to define MS treatment and standards of care for the 21st century, develop a minimum standard of care internationally, and motivate the MS community to align standards of care and challenge the current treatment paradigm. Towards that aim, the Steering Group developed overarching principles to guide management and improve outcomes for people with MS, which were published in their 2012 consensus statement (Rieckmann et al., 2013). Among those principles, the group identified

the patient-centric elements as requiring the most urgent action - in particular, the topic of patient engagement in MS.

**2. Methods**

Two workshops were held to identify themes related to patient engagement that the group felt were of particular importance in the field of MS. In addition to the original Steering Group members, the workshops involved a diverse pool of important stakeholders in MS care including neurologists, an MS nurse, a health economic specialist, a patient group representative, a neuro-rehabilitation specialist and a neuropsychologist.

Five themes were prioritized through discussion and debate, and they constitute the basis of this publication.

Group members independently researched and contributed examples of patient engagement strategies from several countries. Through two additional videoconferences, the group examined interventions that have been successful in areas of patient engagement - not merely in the field of MS, but also in other chronic illnesses that may have overlapping issues with MS. In this publication, the group presents their perspective on these programs, discusses research demonstrating the barriers to achieving patient engagement, and provides practical strategies for overcoming these issues.

### 3. What is patient engagement?

While advances in medicine, technology and healthcare services continue to offer promises of longevity and improved quality of life (QoL), reliance on the patient's knowledge, skills and motivation to access these benefits is increasing. The reasons for this may lie in the need to streamline health services and minimize burden on healthcare providers, fragmented healthcare delivery systems, and the movement away from a paternalistic/authoritarian style of healthcare arising from evidence that patients have better health outcomes when they play a role in their own healthcare (Center for Advancing Health, 2014). The US Center for Advancing Health defines patient engagement (sometimes known as 'patient activation') as 'actions individuals must take to obtain the greatest benefit from the healthcare services available to them' (Center for Advancing Health, 2014). Certainly, with a chronic illness such as MS where novel therapies will most likely influence multiple body systems, a multidisciplinary approach for effective healthcare management is crucial. As such, a 'linchpin' is required to ensure the various sources of care and treatment are coordinated; the concept of patient engagement asserts the patient as that linchpin.

Just as patients are required to change their role from healthcare 'receiver' to 'engager', the role of the healthcare professional also needs to evolve from being a 'provider' of healthcare to become a 'motivator' and 'supporter' of patients to help them achieve this.

### 4. Why is patient engagement so important?

Patient engagement can be practiced at the macro (system), meso (institution), and micro (medical encounter) levels. However, only some patients will wish to be involved at macro or meso levels.

Patient engagement is particularly important in a chronic illness such as MS, which necessitates lifelong therapy. Patients face decisions relating to treatment, interventions and services available, and QoL (Heesen et al., 2011; von Puckler, 2013). Previously, interferon beta or glatiramer acetate therapy was the mainstay of treatment for MS, (National Collaborating Centre for Chronic Conditions, 2004) and their side effects were well known, reversible, predictable, and treatable (Coyle, 2009). However, in the last 10 years, new treatments have emerged which, although beneficial from an efficacy or ease of administration perspective, also have the potential to cause serious side

effects (Girouard and Soucy, 2011; Kieseier et al., 2011). It is imperative that these evolving risks and their relationship to clinical benefit are taken into account by the patient (Clanet et al., 2014).

Patients can play an integral role in improving the quality, safety, and cost of healthcare interventions. As such, the patient has been described as the 'greatest untapped resource in healthcare', and patient engagement termed 'the blockbuster drug of the century' (Chase, 2013). Furthermore, the importance of patient engagement as an essential component of high quality healthcare has been recognized worldwide (Department of Health, 2005a; Aljumah et al., 2013; Institute of Medicine 2014, 2012; Chow et al., 2009). The list of parameters shown to be influenced by patient engagement is extensive and includes improved clinical outcomes, reduced healthcare consumption and improved service quality (Department of Health, 2005a; Chow et al., 2009; Institute of Medicine, 1999; Jha et al., 2008; Meterko et al., 2010; Glickman et al., 2010; Isaac et al., 2010; Charmel and Frampton, 2008; Pietrolongo et al., 2013; Heesen et al., 2013; Coulter, 2012). Improved clinical outcomes shown to equate with patient engagement include improved treatment adherence, faster recovery and reduced mortality rates (Department of Health, 2005a; Chow et al., 2009; Institute of Medicine, 1999; Jha et al., 2008; Meterko et al., 2010; Glickman et al., 2010; Isaac et al., 2010; Charmel and Frampton, 2008; Pietrolongo et al., 2013; Heesen et al., 2013; Coulter, 2012). An analysis of >1800 veterans with myocardial infarction showed that better patient-centered care was associated with a lower hazard of death over a 1-year study period (HR: 0.992; 95% CI: 0.986-0.999) (Meterko et al., 2010).

When patients are engaged with their healthcare, both *reduced healthcare consumption* (including improved health service efficiency, fewer diagnostic tests and referrals, decreased use of healthcare services and lower annual charges) and *patient preference towards less aggressive/costly courses of treatment* are seen (Department of Health, 2005a; Chow et al., 2009; Institute of Medicine, 1999; Jha et al., 2008; Meterko et al., 2010; Glickman et al., 2010; Isaac et al., 2010; Charmel and Frampton, 2008; Pietrolongo et al., 2013; Heesen et al., 2013; Coulter, 2012). For example, patients who are properly informed about their treatment options are less likely to opt for expensive elective surgical procedures where other options exist (Isaac et al., 2010). Improved service quality is observed when patients are engaged, and can include improved communication and health literacy, greater confidence in treatment decisions, decreased malpractice claims, higher hospital staff retention rates, more satisfied patients, and reduced patient-physician discordance (Department of Health, 2005a; Chow et al., 2009; Institute of Medicine, 1999; Jha et al., 2008; Meterko et al., 2010; Glickman et al., 2010; Isaac et al., 2010; Charmel and Frampton, 2008; Pietrolongo et al., 2013; Heesen et al., 2013; Coulter, 2012). In Stamford Hospital, 18 months after implementing a structured approach to patient-centered care, the employee satisfaction rate increased from the 33<sup>rd</sup> to the 60<sup>th</sup> percentile (Charmel and Frampton, 2008). With so much to be gained from patient engagement, efforts to promote this untapped resource are paramount.

**Table 1** Interventions shown to support shared decision-making and health literacy<sup>a</sup>.

Intervention	Potential benefits
<b>Shared decision-making</b>	
Patient decision aids	<ul style="list-style-type: none"> <li>• Increased patient involvement in decisions</li> <li>• Better understanding of treatment options</li> <li>• More accurate perception of risks</li> <li>• Improved quality of decisions</li> </ul>
Health coaching	<ul style="list-style-type: none"> <li>• Does not increase patient's anxiety</li> <li>• Reduced mortality</li> <li>• Reduced risk factors</li> <li>• Improved health status</li> </ul>
Question prompts	<ul style="list-style-type: none"> <li>• Increased question-asking in consultations</li> <li>• <i>May</i> increase patients' knowledge and understanding</li> <li>• <i>May</i> empower patients and improve satisfaction</li> <li>• Does not necessarily increase length of consultations</li> </ul>
Self-management education and support	<ul style="list-style-type: none"> <li>• Improved patient knowledge and understanding</li> <li>• Improved confidence and coping ability</li> <li>• Improved health behaviors</li> <li>• Improved social support</li> <li>• <i>May</i> improve adherence to treatment recommendations</li> <li>• <i>May</i> improve health outcomes</li> <li>• <i>May</i> reduce hospital admission rates</li> </ul>
<b>Health literacy</b>	
Personalized patient information (paper and electronic) reinforced by professional or lay support	<ul style="list-style-type: none"> <li>• Improvements in patients' knowledge and understanding of their condition</li> <li>• Increased sense of empowerment</li> <li>• Greater ability to cope with the effects of illness</li> <li>• Improved patient satisfaction</li> <li>• <i>May</i> lead to improvements in health behavior</li> <li>• <i>May</i> contribute to better health outcomes</li> </ul>
Telephone counseling and help lines	<ul style="list-style-type: none"> <li>• Less social isolation</li> <li>• Improved self-efficacy and satisfaction</li> <li>• Reduced mortality and fewer hospitalizations for some patient groups</li> <li>• <i>May</i> improve diagnostic accuracy</li> <li>• <i>May</i> contribute to improved health status and better QoL</li> </ul>
Motivational interviewing	<ul style="list-style-type: none"> <li>• Better adherence to treatment recommendations</li> <li>• Improved health behavior</li> <li>• Reduced risk factors</li> <li>• Improved health outcomes</li> </ul>

<sup>a</sup>Reproduced and adapted from Coulter et al. Patient engagement-what works? The Journal of Ambulatory Care Management 2012;35:80-9 (Coulter, 2012). Where the evidence is less strong, this is indicated by including *may* in the list of potential benefits.

## 5. What influences patient engagement?

Understanding of patient engagement in MS is in its infancy but the factors influencing engagement appear complex and diverse. One cross-sectional survey of 199 MS patients in Southeast USA, identified that MS-related QoL and MS-related self-efficacy correlated significantly with patient activation in MS patients ( $r=0.42$ ,  $P<0.01$  and  $r=0.50$ ,  $P<0.01$ , respectively). Depression had an inverse correlation ( $r=-0.43$ ;  $P<0.01$ ) (Goodworth et al., 2014). Studies in other disease areas have demonstrated further elements

that may play a role. One review reported five categories of factors influencing engagement: *patient-related* (patients' knowledge/beliefs, demographic characteristics, emotions and coping style); *illness-related* (symptoms, treatment plan, patient's prior experience, illness severity); *healthcare professional (HCP)-related* (HCPs' knowledge and beliefs, HCP role); *healthcare setting-related* (primary or secondary care); and *task-related* (medical knowledge required and whether the required patient behavior challenges clinicians' clinical abilities) (Davis et al., 2007).



## 6. Achieving patient engagement

Understanding the issues that influence patient engagement in MS will facilitate investigation into how these might be overcome.

### 6.1. Theme 1: setting and facilitating engagement by education and confidence-building

A prerequisite to helping a patient become engaged is the establishment of an effective, caring and mutually respectful patient-physician relationship; patients consistently say that good communication with their doctors boosts their confidence with the healthcare process (von Puckler, 2013; Duffy et al., 2004). People prefer to be treated by clinicians who are empathetic listeners and who are good at informing, advising, and educating them (Coulter, 2005; Keating et al., 2002). Moreover, the main independent predictors of patient satisfaction are patients' perceptions of communication and partnership, and a positive approach by the doctor (Little et al., 2001). One study demonstrated that therapist responsiveness in the first two sessions of therapy relates to three measures of early patient engagement in treatment. Using videotapes and data from the NIMH (National Institute of Mental Health) Treatment of Depression Collaborative Research Program (TDCRP), an instrument was developed to measure therapist responsiveness in the first two sessions of Cognitive Behavior Therapy and Interpersonal Psychotherapy. A factor measuring positive therapeutic atmosphere, and a global item of therapist responsiveness, predicted both the patient's positive perception of the therapeutic relationship after the second session and the number of patient's remaining in therapy for more than four sessions. A negative therapist behavior factor also predicted early termination (Elkin et al., 2014). Engagement is vital from the day of diagnosis (Solari, 2014) when the MS patient and their physician embark on a unique journey together and the emotional burden on both parties is high (Solari, 2014). Consequently, the collaborative nature of that initial process and the success in instigating clear, honest communication can determine whether the future relationship will be one of trust and respect and how positively the patient will be involved in their health decisions and management.

There is growing acknowledgment that healthcare professionals require effective communication and conflict management skills (Ha and Longnecker, 2010) despite some receiving little or no focused training in these areas. Some studies point to the need for further empowerment of MS physicians to gain better patient communication skills (Pietrolongo et al., 2013; Kasper et al., 2011; Kasper et al., 2008). Encouragingly though there is evidence that communication skills training is becoming more visible in medical education. Such training is well established in medical schools across the UK, Europe and the USA (Hausberg et al., 2012). In the USA, communication skills feature prominently in clinical skills examinations and are incorporated into residency programs and maintenance certification of practicing physicians (Makoul 2003).

Various practical strategies have been proposed to optimize physician-patient communication. Simple conversational and

listening techniques can be helpful, eg sitting down during a consultation, attending to patient comfort, establishing eye contact, listening without interrupting, showing attention with nonverbal cues such as nodding, allowing silences while patients search for words, acknowledging and legitimizing feelings, explaining and reassuring during examinations, and asking explicitly if there are other areas of concern. The provision of 'prompt sheets' encourages patients to ask questions about their treatment options, patients can be encouraged to bring a list of questions to their clinic visits. Directing patients to access their medical notes promotes transparency and trust, and improves information recall. Tools such as [www.myopennotes.org](http://www.myopennotes.org) provide help in achieving this and, in fact, the patient's right to access their medical notes has been legalized in France through the Kouchner Act, 2004 ([http://lelien.typepad.fr/association\\_le\\_lien/2007/12/accs-aux-inform.html](http://lelien.typepad.fr/association_le_lien/2007/12/accs-aux-inform.html)). However, patients with low levels of health literacy may find this initially challenging. A 'road map' or a set of goals that both physician and patient wish to achieve can be developed and amended throughout the disease course. Shea (2006) also describes a number of useful techniques, such as: learning the patient's belief set; familiarization with the patient's family history/cultural beliefs to discover underlying motivations; providing the patient with a sense of collaboration in the health decision process; and learning the patient's opinion towards taking medication in general (Shea, 2006). In addition, reliable, up-to-date publications and guidance to support physicians in communicating with their patients are provided by the MS Society. Coulter (2012) also provides initiatives that have proven beneficial (Table 1) (Coulter 2012) and Table A1 (Appendix) provides examples that support the use of these initiatives. The *Adopt One! Challenge* <http://mindthegap.smarthealthmessaging.com/2013/08/13/the-adopt-one-challenge-the-first-step-to-better-patient-engagement-patient-experiences-2/> allows physicians to obtain a comprehensive baseline assessment of their patient communication skills, measure how their skills compare with best practice, and access online skills development tools. The program encourages physicians to commit to adopting one new patient-centered communication skill over the course of 12 months and provides online training and resources needed to help them achieve this goal.

Current management guidelines underline the importance of educating and supporting the MS patient. National Institute for Clinical Excellence (NICE) guidelines recommend implementing an education program that takes into account the different aspects of the disease and incorporates guidance on the level of communication, provision of emotional support, encouragement of autonomy/self-management and provision of support to family and carers; <http://www.nice.org.uk/nicemedia/live/10930/46699/46699.pdf>. The European MS Platform's Code of Good Practice (<http://www.emsp.org/attachments/article/134/1code08.pdf>) stresses the importance of accessible information, informed advice and emotional support, and suggests self-help education programs be provided for patients and their carers. The concept of 'therapeutic patient education' has also been enshrined in French law (article 84, Hospitals, Patients, Health and Territory, Law No. 2009-879 of 21 July 2009) and is officially recognized as an integral part of patient care. Specifically, it mandates that patients must receive specialized education related to their condition, which can be delivered by trained 'peer educators'.

**Table 2** Research and development studies evaluating the symptoms of MS that commonly impact on QoL and HR-QoL in MS patients.

Study	Outcome measured	Findings related to the impact on patient QoL/HR-QoL
Vision impairments (Galletta et al., 2012)	EDSS: visual function	Visual dysfunction in benign MS was as marked as that in typical MS and accounted for a substantial degree of disability and loss of QoL (Galletta et al., 2012).
(Mowry et al., 2009)	Low contrast letter acuity	Specific visual disorders measured by low contrast letter acuity may influence QoL (Mowry et al., 2009)
Gait and mobility impairments (Van Asch 2011)	Anonymous online survey on walking and mobility	45% of patients reported mobility difficulties within 1 month of diagnosis, 93% within 10 years. These had a profound effect on independence, employment, loss of earning, HRQoL and ADLs
(Yildiz 2012)	Online 5-question survey evaluating walking speed	Impaired walking speed affected ADLs and avoidance of: walking to the nearest shop (53%), cleaning the home (46%), crossing the street (31%), walking to the post box (29%), visiting neighbors (24%)
Sexual dysfunction (Nortvedt et al., 2001)	SF-36 Health Survey	Present in up 91% of MS patients. May be a direct reflection of MS neurological impairments, side effects of treatments, or indirect changes in sexual responsiveness due to other MS symptoms (eg fatigue, depression, bowel and bladder dysfunction, mobility issues, etc) (Burks et al., 2009). Patients with sexual dysfunction scored lower on all 8 subscales of SF-36, after adjustment for EDSS (Nortvedt et al., 2001). Most significant effects on QoL: perceived social functioning, vitality, perceived general health, depression, ability to form intimate relationships (Burks et al., 2009)
(Burks et al., 2009)	None (overview)	
Mental health problems (Hart et al., 2005)	MSQoL-54, Ryff's Scales of Psychological Well-being: depression	Depression affects HR-QoL, possibly more than physical disability/symptoms. Treatment of major depression significantly improved psychological well-being
(Phillips et al., 2009)	Emotional Regulation Questionnaire, WHOQoL-BREF: emotional adjustment	Failure to use effective emotional reappraisal strategies reduced all aspects of QoL
(Kern et al., 2009)	Symptom Checklist-90-R: psychological distress	Psychological distress in MS patients is associated with neurological disability, but is also present in patients with minimal or no neurological disability. Psychological distress is an independent predictor for MS-related QoL
Cognitive dysfunction (Rao et al., 1991)	A comprehensive neuropsychological test battery	Cognitive dysfunction impacted many aspects of daily functioning, eg work, social and avocational activities, sexual dysfunction, performance of household tasks, psychopathology (Rao et al., 1991).

Table 2 (continued)

Study	Outcome measured	Findings related to the impact on patient QoL/HR-QoL
(Fernandez et al., 2011) (Amato et al., 2001)	MS International QoL Questionnaire (MuSiQoL) A neuropsychological test battery	Cognitive dysfunction is a major factor in determining QoL in MS (Rao et al., 1991; Fernandez et al., 2011) Limitations in a patient's work and social activities correlated with cognitive decline, independent of the degree of physical disability (Amato et al., 2001)
Attention deficit (Phillips et al., 2009)	Cognitive Failures Questionnaire: attentional lapses	Attentional failures - predicted variance in all aspects of QoL (WHOQoL-BREF)
Bladder and bowel problems (Vitkova et al., 2013)	Bladder Control Scale, Bowel Control Scale, Incapacity Status Scale	Bladder dysfunction is associated with a poorer HR-QoL in MS patients even if they have had MS for a relatively short time
Fatigue (Zwibel 2009)  (Nogueira et al., 2009)	Review of PubMed searches on multiple contributors to QoL in MS Fatigue Severity Scale	Fatigue is present in 75-95% of MS patients (Zwibel 2009). Affects physical and mental components of QoL, independent of disability. Impairs vocational abilities and stamina for physical activity; primary cause of MS-related unemployment (Zwibel 2009; Nogueira et al., 2009)
Pain (Svendsen et al., 2005)	SF-36: pain	Pain in MS is associated with pressure pain threshold, cold allodynia, abnormal temporal summation, and mechanical or thermal hyperalgesia. Pain patients scored lower in all dimensions of SF-36 compared with pain-free and healthy subjects
Sleep disturbances (Merlino et al., 2009)	Pittsburgh Sleep Quality Index (PSQI), Charlson Comorbidity Index (CCI), SF-36 Italian version	Poor sleep present in almost 50% of MS patients. Independent predictor of QoL on various measures of QoL. Can result from pain, bladder and sexual dysfunction and other clinical conditions

## 6.2. Theme 2: patient-reported outcomes: increasing the importance placed on QoL and patient concerns

MS patients rank their QoL as lower than the general public, and lower than those with other chronic diseases (Rudick et al., 1992; Riazi et al., 2003; Burden of illness of multiple sclerosis, 1998). The wide-ranging effects of MS impact an individual's QoL at psychological, physical, social and financial levels, throughout all stages of the disease (Miller and Allen 2010; Mitchell et al., 2005). However, clinical focus on MS has relied heavily on the Expanded Disability Scale Score (EDSS) - a measure of disease activity weighted towards the physical, especially mobility, aspects of the disease (Kurtzke, 1983). More recently, however, the importance of MS outcome assessment from the patient's perspective has been recognized.

Patient-reported outcomes (PROs) include information provided by the patient that reflects their functioning health and well-being from their perspective, including how the disease and medical interventions impact on their QoL. PROs introduce a more holistic approach to disease management by incorporating outcomes affecting the patient across many aspects of their QoL. The diverse subjective symptoms associated with loss of QoL are difficult to quantify, hence discrepancies arise between patient and physician perceptions over which domains of health are the most crucial (Rothwell et al., 1997). Nonetheless, patients report symptoms earlier and more frequently than clinicians do, (Basch, 2010) and patients' reports are more highly concordant with overall health status than clinicians' reports (Basch, 2010). Integrating PROs into clinical practice has the potential to capture those benefits and enrich the clinical encounter (Miller and Allen, 2010).

The major factors contributing to health-related QoL (HR-QoL) of the MS patient include the ability to perform activities of daily living (ADLs), patient well-being, satisfaction with life, and the impact of disease-related symptoms on these parameters (Burden of illness of multiple sclerosis, 1998). Table 2 shows the results from selected studies that have investigated the symptoms of MS that commonly impact on QoL and HR-QoL in MS patients. The challenge to the physician is to identify a management plan to address the range of symptoms impacting each individual's QoL.

To date, numerous PRO QoL measures have been developed specifically for MS, (Vickrey et al., 1995; Cella et al., 1996; Ritvo et al., 1997; Hobart et al., 2001; Ford et al., 2001; Doward et al., 2009; Meads et al., 2009) but no particular measure has gained wide popularity or consensus (Solari, 2005). There are practical considerations when incorporating a PRO measure into clinical practice. These include deciding which measure to use and the frequency with which it should be conducted, finding an appropriate setting and mode of administration, identifying aids to interpret the data, achieving the 'buy-in' of institute staff and patients, sourcing and maintaining appropriate equipment, minimizing disruption to healthcare delivery, and allowing sufficient time for implementation.

Both digital-based technology and more traditional interview methods may have a role in PRO measurement and should be evaluated for acceptability in the environment in which they are to be used. The Multiple Sclerosis Documentation System 3D (MSDS 3D) is an innovative computer-based documentation system being used successfully in clinical practice in Germany to integrate data provided by the patient, the MS nurse and the physician (Schultheiss et al., 2012; Ziemssen et al., 2013).

Incorporation of PRO QoL measures in clinical practice is likely to escalate as our understanding of them increases. Already, they have been included as a central element of healthcare evaluation and health service evaluation, disease registries, epidemiological studies, drug R&D, and clinical trials (Riazi, 2006).

### 6.3. Theme 3: providing credible sources of accurate information

Considering the complexity of MS disease pathology and the intricacy of the management options available, provision of trusted, accurate and relevant information is paramount to an MS patient (von Puckler, 2013). A recent Cochrane review determined that information provision to people with MS increased disease-related knowledge with no negative side effects (Köpke et al., 2014). In 65% of clinic visits the patient's desire for health information is underestimated (Waitzkin, 1984). One study highlighted a deficit between the information patients were receiving and the amount of information they actually wished to receive from various sources. While the amount of information provided by MS societies and MS specialist nurses was considered close to ideal, many patients wished to receive significantly more information from GPs, eye specialists, neurologists, and from education sessions (Matti et al., 2010).

Unsurprisingly, mass media, rather than interpersonal information sources, are the first route of information accessed by

many people with MS concerns (Marrie et al., 2013). However, understandably, many patients have concerns about the quality of that information (Marrie et al., 2013). One study showed that the most trusted information source was the physician, with 98% reporting that they trusted a physician 'some' or 'a lot' (Marrie et al., 2013). In another study, two-thirds of patients were reluctant to discuss internet information with their physician (Hay et al., 2008). Therefore, some patients are exposed to information that is not reliable, and of which their physicians are not aware, nor able to provide their reaction or opinion (Ball and Lillis, 2001; Potts and Wyatt, 2002). A possible barrier to discussing internet-derived information is fear of perceived lack of confidence in the physician. Consequently, the MS physician needs to be prepared to open discussions regarding the accuracy and reliability of this source of information from the first consultation, and to reassure the patient that they are open to discussing information they access.

Internet-based information can help bridge the gap between doctor and patient and elevate the level of dialog. However, lack of quality control of such information has led to the development of health website evaluation tools to help direct patients to accurate sources of information. These tools have revealed excellent websites that can meet nearly all of the information needs of people with MS (Harland and Bath, 2007). To our knowledge, there is currently no widely acknowledged quality certification for MS websites, although these do exist in other disease areas. One such scheme undertaken by a French rheumatoid arthritis (RA) patient organization provides a quality rating for RA websites that is arbitrated by both health professionals and patients (<http://www.polyarthrite-andar.com/article171.html>). This is possibly an area for future focus in MS.

Patients can be supported to self-regulate the information they access and how they interpret it. Some websites provide useful commentary by MS experts, helping patients interpret trial data and understand their likely impact (<http://multiple-sclerosis-research.blogspot.co.uk/>). The Multiple Sclerosis International Federation (MSIF) has published guidance for patients on issues to consider when assessing online content regarding MS, (Shaw, 2014) which includes:

- check who is responsible for developing the content of the website and consider their reasons for providing the information;
- check whether the content seems reliable, complete and current, and check against other sources;
- check that the website presents a broad and unbiased view in an easy-to-read format;
- check that the website's privacy policy and disclaimers are clear and accessible;
- even if a website looks professional it does not mean it is, check its credentials;
- check the website's country of origin; treatments or services may not be available in every country.

As well as the risk of misinformation, unfettered access to MS information has the potential to overwhelm a patient and cause them anxiety. To help avoid this, information regarding MS can be sensitively phased or layered in topic, rate and complexity, depending on the desire and needs of the individual patient. Modern technology allows an effective and cost



-efficient way to achieve this. Giovannoni's 'tube map' for MS care highlights what information and support is required throughout all stages of the disease (Fig. 1).

Owing to the complexity of MS, helping a patient to improve their health literacy - the capacity of the patient to obtain, process and understand basic health information and services needed to make appropriate health decisions - is beneficial. Interventions associated with improved health literacy are shown in Table 1 (Coulter, 2012). However, the impact of information is greater when accompanied by verbal reinforcement by a physician (Coulter, 2012) - and the MS physician and their medical team are in the ideal position to act as a trusted sounding board for a patient with MS.

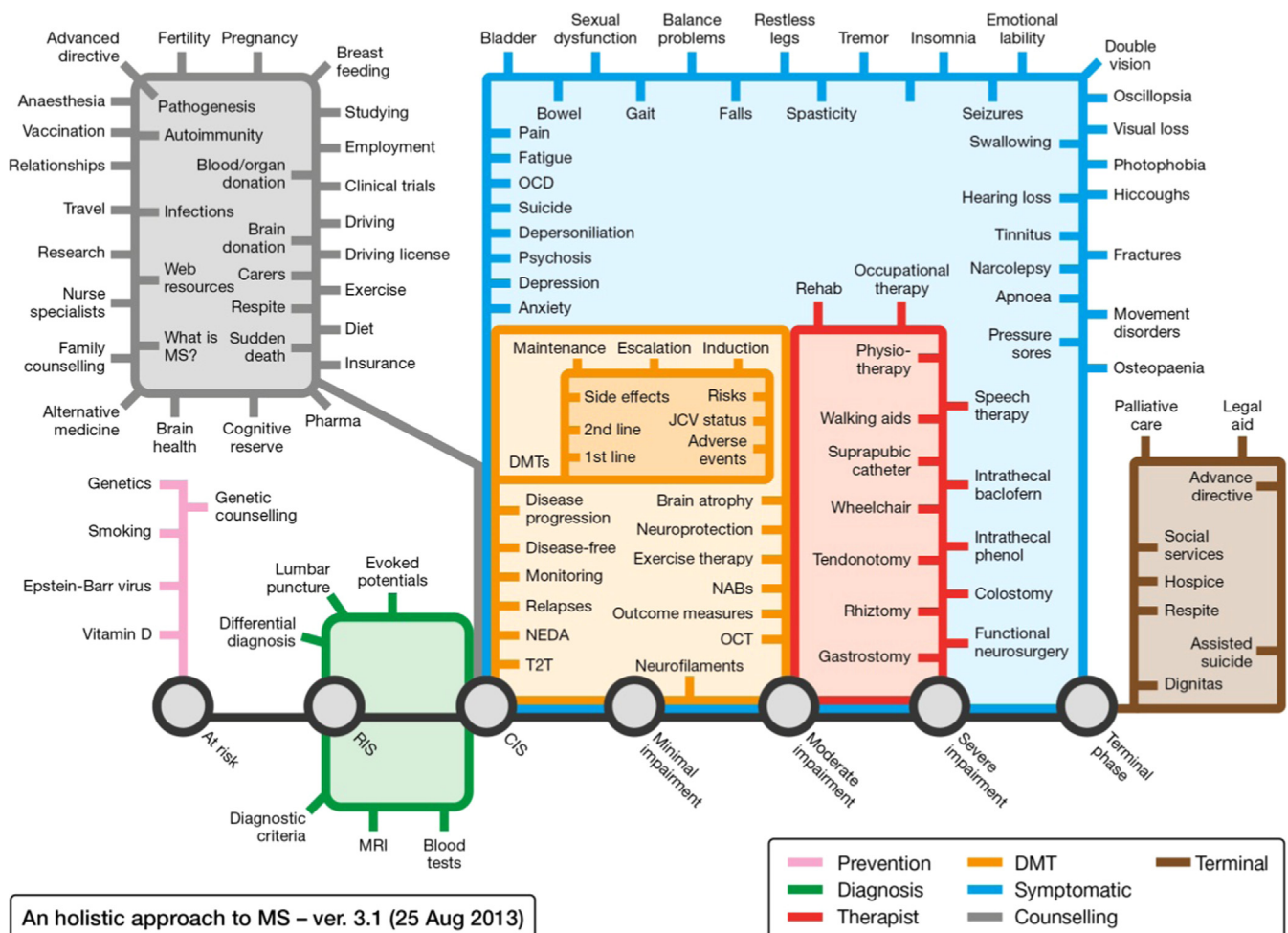
One way of supplementing the education and support provided by physicians and MS nurses is through specialist MS group therapeutic education programs, which can take the form of group seminars or workshops, and may reinforce disease and treatment information, physical rehabilitation and psychological counseling. They have been shown to improve patient coping strategies, patient satisfaction, psychological difficulties, QoL and treatment persistence (Colpaert, 2010; Gallien et al., 2014; Mazaheri et al., 2011; Rat, 2013). These may represent a resource-effective way

of providing additional information to MS patients, but analysis on cost-effectiveness and ways to ensure uptake across sub-populations are required (Plow et al., 2010).

#### 6.4. Theme 4: encouraging treatment adherence through engagement

With the availability of disease-modifying therapies for MS, problems with adherence to these complex treatment regimens under chronic conditions have been observed (Klauer and Zettl, 2008). In developed countries, treatment adherence among patients with MS is a mere 41% (Steinberg et al., 2010). Considering that lack of adherence to interferon beta treatment in MS correlates with a loss of efficacy, higher relapse rate and higher utilization of health resources, (Steinberg et al., 2010) this remains an area for concern for treating physicians (Martin et al., 2005).

The causes of non-adherence in MS are complex and are reported to include forgetting medication, MS-related disability affecting ability to medicate, patient disagreement with need for treatment, cost, poor social support (Girouard and Soucy, 2011; Martin et al., 2005; Lugaresi et al., 2012; Cerghet et al.,



**Fig. 1 Multiple sclerosis tube map.<sup>a</sup>** Redrawn and adapted with permission of Professor Gavin Giovannoni. © Gavin Giovannoni. The schematic demonstrates the breadth of information required by the MS patient throughout the course of their illness. To optimize the impact, information can be layered to a rate and depth relevant to the individual patient. Forthcoming versions of the tube map will include such layering.

2010; Saunders et al., 2010) and patients forgetting to take their medication Treadaway et al., 2009. However, sometimes treatment adherence reflects the interpersonal dynamics of the physician-patient relationship (Martin et al., 2005). In the field of HIV there is evidence to suggest that good physician-patient relationships are correlated with better adherence to antiretroviral regimens. A small Italian study suggests that this may also be the case in MS. Patient-perceived utility of treatment significantly correlated with patients having confidence in the clinical staff, to their perception of being involved in therapeutic decision making ( $P < 0.05$ ), and to long-term therapy adherence ( $P = 0.0001$ ) (Koudriavtseva et al., 2012). Other studies have shown that the aspects of the physician-patient relationship associated with higher rates of therapy adherence include general communication, overall satisfaction, willingness to recommend, physician trust, disease-specific communication, and adherence dialog (Schneider et al., 2004).

The goals of the healthcare professional, with respect to adherence, could be to motivate the patient to take the medication correctly, to adhere to the prescribed schedule and to keep follow-up appointments. Other support strategies might include sending reminders, providing information that the patient can consult after the appointment, helping the patient understand the importance of adherence, listening to individual concerns, and offering praise and encouragement (Kinnersley et al., 2007; Smrka et al., 2010). Remington et al. provide a thorough list of possible interventions to promote adherence in MS (Remington et al., 2013). Various methods have demonstrated efficacy in improving adherence to therapy in MS. Several studies have reported an association between improved adherence and nurse-based telephone counseling (Caon et al., 2010) motivational interviewing has also had a beneficial effect on adherence (Caon et al., 2010). Telephone-based CBT for the treatment of depressive symptoms has shown to be more efficacious at improving adherence to interferon beta-1a therapy after 4 months compared with usual care for depression (Mohr et al., 2000).

### 6.5. Theme 5: empowering through a sense of responsibility

The responsibility to engage the MS patient in their health lies with everyone involved with their care, as well as with the patient themselves. Harnessing this sense of responsibility on all levels may be instrumental in empowering engagement.

In an attempt to provide a comprehensive picture of the demands imposed upon the individual by current healthcare delivery practices in the USA, the US Center for Advancing Disease developed a national Engagement Behavior Framework (Table A2 Appendix) (Center for Advancing Health, 2014). On a clinical level, the framework serves to help the patient understand the extent to which they need to become involved to leverage healthcare resources, which could help galvanize the patient into action. It could also help identify areas that are difficult for the patient to achieve and a platform for discussing these concerns with the physician. On a system level, it helps highlight the scope of challenges facing patients in maximizing their care, identifies knowledge gaps, sets priorities for new research and commissions reviews to consolidate knowledge (Center

for Advancing Health, 2014). Bernabeo et al. (2013) have also published a set of key competencies that are required on a patient, physician and system level in order to achieve shared decision-making (Bernabeo and Holmboe, 2013).

Whether a patient becomes engaged in their care is a choice for the individual but considering the benefits to the patient, encouraging engagement is ethically sound. Instilling a sense of societal responsibility in the patient might be beneficial - with regard to their responsibility to use the resources available in the most responsible manner. Some patients - for example, the 'pragmatic', 'consistent' or 'hungry' patient (Table 2) - may feel more engaged in their care if they are involved on a meso or macro level, becoming involved in drug development, healthcare policies, patient advocacy/support, fundraising, and local MS Society activities. Initiatives such as the FDA Patient Network (<http://patientnetwork.fda.gov/>) and the MS Society's Research Network (<http://www.mssociety.org.uk/ms-research/get-involved-research/research-network/whats-involved>) provide avenues through which some patients may gain empowerment. A sense of responsibility may also be fostered by a patient becoming a patient-educator for other patients or medical professionals. This has been shown to be a rewarding and therapeutic experience (Anderson et al., 2003; Muir, 2007), with benefits such as raising self-esteem and empowerment, gaining new insights into their own issues, fostering a better understanding of the patient-doctor relationship, companionship, and improved QoL (Towle et al., 2010; Gecht, 2000; Walters et al., 2003). However, the patient needs support in managing the potential challenges of undertaking such a role (Lauckner et al., 2012). Lay or community teaching is evolving and becoming an accepted method of teaching patient-centric care. In some countries, such as the UK, patient involvement in health professional education is mandated by the government.

## 7. Discussion

By its nature, this paper is selective in its approach and its themes represent the primary thoughts of the MS in the 21st Century Steering Group in relation to topics that have the potential to influence patient engagement in MS.

Whilst appreciation has been accumulating for the critical role played by the patient in the effectiveness of healthcare, we are now observing a shift in the way patients are being compelled to get involved in the healthcare process, and this has the potential to become a strong framework for achieving patient engagement. PROs are becoming more integral to clinical trial protocols, management guidelines are becoming more reflective of patient-centric issues, and therapeutic patient education for chronic conditions has found legal sanction in some countries. Yet, what appears to make a critical difference to a patient's experience of MS is their personal relationship with their healthcare provider. This is the central foundation of patient-centeredness and the key to motivating a patient to be engaged in their own care.

However, developing rapport takes time, which is not currently afforded to physicians on a consistent basis under current healthcare systems. Time constraints remain the most frequently cited barrier to implementing the process of shared decision-making in the clinical setting (Gravel et al., 2006) - and indeed to

any change in clinical practice (Legare and Witteman 2013). Hence, promotion of effective integration of patient engagement requires commitment from those developing healthcare systems. In addition to time constraints, increasing pressure is being placed on physicians to acquire further competencies to aid patient engagement. Integration of such skills into medical training is likely to be a worthwhile endeavor. However, healthcare organizations and policy makers need to analyze the ways in which their policies are preventing patient engagement from currently succeeding. Certainly, further research is required to explore the impact of payment schemes to promote integrated chronic care and financially support patient engagement (Tsiachristas et al., 2013). While we recognize that implementing procedures and policies to positively influence patient engagement takes additional resources, achieving this from an early stage will likely improve healthcare efficiency in terms of patient (and healthcare professional) satisfaction, clinical outcomes, costs, and time.

As well as financial and policy constraints, the prevailing social and cultural environment is also likely to impact considerably on the emphasis of shared decision-making and, consequently, patient engagement. Particularly in an age of multiculturalism, patients and their physicians can bring a mixture of social and cultural-specific ideas and values to the medical interaction, and to their thoughts and expectations as to how health should be managed. Physicians can help transcend these differences by learning about the social and cultural beliefs of their patients, remaining non-judgmental when differences arise, and by paying close attention to signals of discontent or lack of engagement from the patient.

The way in which patients engage in their healthcare is very personal and will fluctuate throughout the course of the disease but is critical to optimizing healthcare benefits. This is a challenging role that requires the patient to be motivated, insightful and aware, which will not always be possible throughout the course of the disease. The role of the healthcare professional, and critically the MS nurse, is to help support the patient in this engaged role. The consequences of patients not engaging will be borne most heavily by the patients themselves and their families, in the form of emotional, physical, social and financial costs; but it also impacts heavily on healthcare systems and society with respect to wasted resources, suboptimal outcomes and increases in health disparities. All stakeholders need to demonstrate an ongoing commitment to ensure that every MS patient takes the opportunity to participate appropriately in their care.

## Conflict of interest statement

We wish to draw the attention of the Editor to the following facts which may be considered as potential conflicts of interest and to significant financial contributions to this work.

### Dr Celia Oreja-Guevara

Received honoraria Biogen-Idec, Novartis, Genzyme, Almirall, Merck-Serono.

### Dr Gisela Kobelt

Continuing to be on advisory boards and speak at MS meetings organised by companies marketing MS drugs. The companies are Biogen, Serono, Sanofi, Novartis.

### Dr Sven Schippling

Received consulting and speaker fees and travel grants from Biogen Idec, Bayer Merck Serono, Genzyme/Sonafi-Aventis, Novartis, TEVA and research grants from Bayer, Biogen Idec, Bayer Merck Serono, Genzyme/Sonafi-Aventis, Novartis.

### Ms Heidi Thompson

Educational Grant Received from Martha Mc Menamy Fund 2012. Travel Grants received from Teva pharmaceuticals, Merck Serono & Biogen Idec. Consultancy fees received from Merck Serono & Biogen Idec

### Professor Dawn Langdon

Professor Langdon has received funding for travel to scientific meetings from Bayer Healthcares, Serves on a Steering Committee for Bayer Healthcare, has served/serves as a consultant to Merck-Serono, Novartis, Bayer Healthcare, served on speaker contract funding from Bayer Healthcare, Novartis and Biogenidec and receives educational grants and sponsorship from Bayer Healthcare.

### Professor Irina Elovaara

Irina Elovaara has received travel grants and honoraria (lectures, advisory boards, consultations) from Schering, Merck Serono, Teva, Novartis, Biogen, Sanofi-Aventis, Genzyme and Octapharma.

### Professor Jacques LeLorier

Acted as a consult and involved in research projects.

### Professor Patrick Vermersch

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### Dr Sarah Morrow

Received investigator initiated grants from 2 pharmaceutical companies. Acted as a consult and been involved in advisory boards. Site PI for a pharmaceutical run multicenter RCT. Companies are: Biogen Idec, EMD Serono, Genzyme, Novartis Canada.

### Professor Diego Centonze

Dr. Diego Centonze is an Advisory Board member of Bayer Schering, Merck-Serono, Teva, Biogen Idec, GW Pharmaceuticals, Almirall, Genzyme, Novartis and received honoraria for speaking or consultation fees from Almirall, Bayer Schering, Biogen Idec, Genzyme, GW Pharmaceuticals, Merck Serono, Novartis, Sanofi-Aventis, Teva, Almirall. He is also an external expert consultant of the European Medicine Agency (EMA), and the principal investigator in clinical trials for Bayer Schering, Biogen Idec, Novartis, Merck Serono, Sanofi-Aventis, Teva, Roche.

### Professor Eva Havrdova

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Canbex - Clinical advisor regarding the development of VSN16

GW Pharma - consultancy fees for advisory board meeting and speaking at launch of Sativex in Norway

Merck-Serono - consultancy fees for advisory board meetings.

Novartis - Steering committee member on Fingolimod and Siponimod trials. Consultancy fees for advisory board meetings. Honoraria for participating and speaking at STEP programme

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Fiveprime - Consultancy fees in relation to clinical development programme

Ironwood - Consultancy fees in relation to clinical development programme

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We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us.

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

We understand that the Corresponding Author is the sole contact for the Editorial process (including Editorial Manager and direct communications with the office). He/she is responsible for communicating with the other authors about progress, submissions of revisions and final approval of proofs. We confirm that we have provided a current, correct email address which is accessible by the Corresponding Author.

**Table A1** Interventions shown to support shared decision-making and health literacy: study findings (Coulter, 2012).

Intervention	Study findings
<b>Shared decision making</b>	
Patient decision aids	<ul style="list-style-type: none"> <li>Numerous randomized trials indicate that patient decision aids improve decision quality and prevent overuse of options that informed patients do not value. Therefore, they have a potential role in reducing unwarranted variations in the use of preference-sensitive health-care options (O'Connor et al., 2009).</li> </ul>
Health coaching	<ul style="list-style-type: none"> <li>Targeted coaching can have a beneficial effect on risk factors and health outcomes, and improvements in health behaviors (Clark et al., 2010; Hutchison and Breckon 2011; Neubeck et al., 2009)</li> </ul>
Question prompts	<ul style="list-style-type: none"> <li>Can help increase the number of questions asked in a consultation but does not necessarily improve patient knowledge (Gaston and Mitchell 2005; Harrington et al., 2004; Kinnersley et al., 2007; Wetzels et al., 2008)</li> </ul>
Self-management education and support	<ul style="list-style-type: none"> <li>Can improve knowledge, coping behavior, adherence to treatment recommendations, and self-efficacy (Chodosh et al., 2005; Foster et al., 2007)</li> </ul>
<b>Health literacy</b>	
Personalized patient information (paper and electronic) reinforced by professional or lay support	<ul style="list-style-type: none"> <li>Improves patient knowledge and understanding of their disease (Kinnersley et al., 2007; Stacey et al., 2011).</li> <li>Targeted, well-designed interventions can help increase knowledge and understanding in people with low levels of health literacy (Pignone et al., 2005)</li> <li>Can help increase sense of empowerment, ability to cope and reduce anxiety (Bessell et al., 2002; Eysenbach 2003; Eysenbach et al., 2004; Wofford et al., 2005)</li> </ul>
Telephone counseling and help lines	<ul style="list-style-type: none"> <li>Can reduce isolation, increase decision-making confidence, and improve satisfaction (Jennett et al., 2003; Mair and Whitten, 2000).</li> </ul>
Motivational interviewing	<ul style="list-style-type: none"> <li>A systematic review of 72 studies found that motivational interviewing in a scientific setting to stimulate healthy behaviors, outperforms traditional advice-giving in the treatment of a broad range of behavioral problems and diseases (Rubak et al., 2005).</li> </ul>



**Table A2** Engagement Behavior Framework devised by the US Center for Advancing Disease - a qualitative description of behaviors that US patients must perform to optimally benefit from their care ([Center for Advancing Health 2014](#)).

1. Find safe, decent care	<ul style="list-style-type: none"> <li>• Find provider(s) who meet personal criteria (eg performance, cost, geographic access, personal style), will take new patients and accept personal insurance</li> <li>• Use available comparative performance information (including cost data) to identify prospective providers</li> <li>• Establish a relationship with a healthcare professional or group</li> </ul>
2. Communicate with healthcare professionals	<ul style="list-style-type: none"> <li>• Seek and use the appropriate healthcare setting when professional attention is required</li> <li>• Prepare in advance of out-patient and in-patient contact, list of questions/issues for discussion with the healthcare professional</li> <li>• Bring list of all current medications (including supplements and alternative products) and be prepared to discuss their benefits and side effects</li> <li>• Report accurately on the history and current status of physical and mental symptoms</li> <li>• Ask questions when any explanations or next steps are not clear and express any concerns about recommendations or care experiences</li> </ul>
3. Organize healthcare	<ul style="list-style-type: none"> <li>• Make appointments; inquire about no-show policies; arrive on time</li> <li>• Assess whether facility can accommodate unique needs (eg physical navigation, hearing or visual impairment, translation services) and arrange for assistance</li> <li>• Bring documentation of health insurance coverage</li> <li>• Bring another person to assist patient if frail, confused, unable to move around or unable to remember the conversation with the provider</li> <li>• Bring a summary of medical history, current health status and recent test results to visits as appropriate</li> <li>• Ensure that relevant medical information is conveyed between providers and institutions</li> </ul>
4. Pay for healthcare	<ul style="list-style-type: none"> <li>• Obtain all test results and appointment records, and maintain personal health record</li> <li>• Compare insurance coverage options, match to personal values, needs and preferences, and select coverage</li> <li>• Gather and submit relevant eligibility documentation if applying for or seeking to maintain public insurance (eg Medicaid, Medicare, SCHIP), compare coverage options if applicable, match to patient's own values, needs and preferences, and select coverage</li> <li>• Before seeking treatment: ascertain cost, benefit coverage restrictions and incentives such as mental health benefits limitations, pre-certification requirements, access restrictions to specialists or adjunct health providers, variables in co-pays for specific types of care or providers</li> <li>• Maintain or adjust coverage in the event of unemployment, eligibility or family status changes (ie change of job, marriage, divorce, birth of child)</li> <li>• Maintain all receipts for drugs, devices and services; submit any documentation of services and/or payments upon request or as needed for third-party payers (eg private insurance, medical/flexible health savings accounts or public payers) and submit payment; negotiate schedule and amount if necessary</li> </ul>
5. Make good treatment decisions	<ul style="list-style-type: none"> <li>• Gather additional expert opinions on any serious diagnosis prior to beginning any course of treatment</li> <li>• Ask about the evidence for the efficacy of recommended treatment options (risks and benefits)</li> <li>• Evaluate treatment options</li> </ul>
6. Participate in treatment	<ul style="list-style-type: none"> <li>• Negotiate a treatment plan with the provider(s)</li> <li>• Learn about any newly prescribed medications and devices, including possible side effects or interactions with existing medications and devices</li> <li>• Fill or refill prescriptions on time, monitor medication effectiveness and consult with prescribing clinician before discontinuing use</li> <li>• Maintain devices</li> <li>• Evaluate and receive recommended diagnostic/follow-up tests in discussion with healthcare providers</li> <li>• Monitor symptoms/condition, including danger signs that require urgent attention (eg for diabetes - monitor glucose regularly, check feet; for depression - medication and/or counseling and monitor symptoms; for hypertension - measure blood pressure regularly, maintain blood pressure diary)</li> </ul>
7. Promote health	<ul style="list-style-type: none"> <li>• Set priorities for changing behavior to optimize health and prevent disease, and act on them</li> <li>• Identify and secure services that support changing behavior to maximize health and</li> </ul>



Table A2 (continued)

1. Find safe, decent care	<ul style="list-style-type: none"> <li>Find provider(s) who meet personal criteria (eg performance, cost, geographic access, personal style), will take new patients and accept personal insurance</li> <li>Use available comparative performance information (including cost data) to identify prospective providers</li> <li>Establish a relationship with a healthcare professional or group</li> <li>Seek and use the appropriate healthcare setting when professional attention is required functioning, and maintain those changes over time</li> <li>Manage symptoms by following treatment plans, including diet, exercise, and substance use agreed upon by the patient and his or her provider</li> </ul>
8. Get preventive healthcare	<ul style="list-style-type: none"> <li>Evaluate recommended screening tests in discussion with healthcare provider</li> <li>Act on referrals for early detection screenings (eg breast cancer, colon cancer), and follow-up on positive findings</li> <li>Get recommended vaccines and participate in community-offered screening/wellness activities as appropriate</li> </ul>
9. Plan for the end of life	<ul style="list-style-type: none"> <li>Complete advance directives and medical power of attorney, file with personal/home records</li> <li>Discuss with/deliver to family physician and other healthcare providers, appropriate family and/or significant others</li> <li>Review documents annually; update and distribute as needed</li> </ul>
10. Seek health knowledge	<ul style="list-style-type: none"> <li>Assess personal risks for poor health, disease and injury, and seek knowledge about maintaining health and caring for one's self</li> <li>If diagnosed with a chronic disease, understand the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health/disease knowledge</li> <li>Know personal health targets (eg target blood pressure) and what to do to meet them</li> </ul>

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## Appendix

See Tables A1 and A2.

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